MENTAL RETARDATION
and
DEVELOPMENTAL DISABILITIES
ELIGIBILITY HANDBOOK

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KANSAS DEPARTMENT OF SOCIAL AND REHABILITATION SERVICES
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HOW TO USE PROTOCOLS

The Mental Retardation Protocol and the Developmental Disability Protocol are designed to ask a series of questions about the person for whom eligibility is being determined. These questions are listed in the left column, with pictures of traffic lights to the far left. As long as the traffic light is green, you may continue to move through the questions, each representing a criterion that must be met in order to be found eligible. If you encounter an amber light proceed with caution until the next red or green light. If at any time the result of your answers is a red light, the person is ineligible and you need go no further.

Some words are **highlighted in green**. These words are defined in the Glossary. Items **highlighted in blue** are documents which are to be used as companions to the protocol. Information in the right column is intended to explain the purpose of the definitional component in the questions on the left. These explanations, along with the definitions in the Glossary, should be used to help you apply the definitional components to the information you have collected about the person.

WHAT IS MENTAL RETARDATION?

Mental retardation is a mental disability that limits the intellectual capacity of an individual. People with mental retardation are those who develop at a below average rate and experience difficulty in **learning** and social adjustment. Mental retardation is not a disease, nor should it be confused with **mental illness**.

In order to be diagnosed with mental retardation, an individual must be evaluated by a person trained and licensed to make such a diagnosis. The evaluation includes intellectual testing and a review of adaptive functioning. A diagnosis of mental retardation requires that both below normal intellectual functioning and significant limitations in adaptive functioning must be present prior to age 18.

MENTAL RETARDATION ELIGIBILITY PROTOCOL

CRITERIA

A. Does the person have **a documented** **Axis II diagnosis of mental retardation** made by a **healthcare professional who is licensed to make a DSM-IV-TR diagnosis?**

1. Yes - The person is eligible; go no further.

2. No - Has the person ever had a psychological evaluation?

a.) Yes - If there is no evidence of an Axis II diagnosis of mental retardation, does the person have any other mental and/or physical condition which could be considered in determining developmental disability (excluding **mental illness** and infirmities of aging.)

(i) Yes - Follow the **DEVELOPMENTAL DISABILITY ELIGIBILITY PROTOCOL.**

(ii) No - The person is not eligible; send a written notice, including

FURTHER EXPLANATION

Examples of healthcare professionals in Kansas who can make an independent DSM-IV-TR diagnosis include: Licensed Psychologist (LP); Licensed Specialist Clinical Social Worker (LSCSW); Licensed Clinical Professional Counselor (LCPC); Licensed Clinical Psychotherapist (LCP); and, Licensed Clinical Marriage and Family Therapist (LCMFT), or Medical Doctor (MD). Making a diagnosis of mental retardation can be challenging and in some cases may require the application of clinical judgment. Healthcare professionals who are licensed to make a DSM-IV-TR diagnosis may use previously completed IQ testing and adaptive behavior assessments to make their diagnosis of Mental Retardation even though those assessments may not have been completed by a person qualified to make a diagnosis of Mental Retardation. Most often this would include information from school psychologists used to determine an exceptionality for special education eligibility.

"The essential feature of Mental Retardation is significantly sub-average general intellectual functioning (Criterion A) that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communications, **self-care**, home living, social/interpersonal skills, use of community resources, **self-direction**, functional academic skills, work, leisure, health, and safety (Criterion B). The onset must occur before age 18 years (Criterion C)."

the right to a local independent **reconsideration** **consistent with HCP/CDDO policy regarding eligibility determination.**

b.) No - Refer the person to a **healthcare professional that is licensed to make a DSM-IV-TR diagnosis.**

B. Did the **qualified person** provide a valid Axis II diagnosis of mental retardation?

1. Yes - The person is eligible; go no further.

2. No - Follow steps A.2.a) (i)(ii) above.

(***Diagnostic and Statistical Manual of Mental Disorders,*** **Fourth Edition, Text Revision. Washington, DC, American Psychiatric Association, 2000. p. 41.)**

"A valid diagnosis of mental retardation is based on three criteria reflecting intellectual functioning level, adaptive skill level, and chronological age at onset."

1. Intellectual functioning level...the principal measure is the intelligence quotient (IQ) as derived from a standardized intelligence test **(e.g., Wechsler Intelligence Scales for Children, 3rd Edition; Weschsler Adult Intelligence Scale, 3rd Edition; Stanford-Binet-IV; Kauffman Assessment Battery for Children).** If a standardized measure of intelligence is available that is appropriate for the individual's cultural, linguistic, and social background, this determination is made on the basis of an IQ of approximately 70 to 75 or below...the assessment of intellectual functioning must involve use of a reliable, valid, and standardized individual intelligence test and be conducted by a competent, well-trained person, under favorable circumstances, and on an individual basis. Under no circumstances should a group test of intelligence be the sole determinate of IQ or a diagnosis of retardation. **In the 2002 AAMR system, the "intellectual functioning"**

criterion for diagnosis of mental retardation is approximately two standard deviations below the mean, considering the Standard Errors of Measurement (SEM) for the specific assessment instruments used and the instruments' strengths and limitations. (*Mental Retardation: Definition, Classification, and Systems of Supports.* Tenth Edition. Washington, DC. American Association on Mental Retardation, 2002.)

2. Adaptive skill level. The second criterion is that the sub-average intellectual functioning is accompanied by related limitations in adaptive behavior...a valid determination of a person's adaptive skill level requires the user of an adaptive skill assessment to evaluate the person's adaptive skill profile on an appropriately normed and standardized instrument. Such a profile reflects the person's strengths and weaknesses across representative adaptive skill areas. **In the 2002 AAMR system, it is important to note that the operational definition of a significant limitation in adaptive behavior was revised and requires performance that is at least two standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, and practical skills. Examples of current adaptive behavior measures in use include: AAMR Adaptive Behavior Scale – School and Community; Vineland Adaptive Behavior Scales; Scales of Independent Behavior-Revised; and Comprehensive Test of Adaptive Behavior-Revised.**

(*Mental Retardation: Definition, Classification, and Systems of Supports.* Tenth Edition. Washington, DC. American Association on Mental Retardation, 2002.)

3. Age of onset. The third criterion requires the documentation that the condition of mental retardation manifests prior to age 18..." **In the 2002 AAMR system, it is noted that documented age of onset can be become problematic for older individuals. Each of these situations may require the use of clinical judgment to make decisions and/or to integrate the input from an interdisciplinary team or from select informants who know the person well and can give reliable and valid information. (*Mental Retardation: Definition, Classification, and Systems of Supports.* Tenth Edition. Washington, DC. American Association on Mental Retardation, 2002.)**

Note: If you believe a diagnosis is not valid, because it does not meet the requirements outlined above, you should question the person who made the diagnosis. **(e.g., Request copies of supporting documentation used to make diagnosis or have the determination reviewed by an independent third party as outlined in HCP/CDDO Eligibility Determination policy.)**

WHAT DOES DEVELOPMENTAL DISABILITY MEAN?

In a nutshell, the definition of developmental disability can be summarized as "a severe, chronic set of **functional limitations** which may result from any physical and/or mental impairment" (Gollay, 1979, p.3) and which are readily apparent before age 22. A critical feature of the definition is the pervasiveness of the effect a developmental disability has on the person's ability to function.
Each component of the definition must be viewed as an individual criterion, composing a set of criteria, each of which must be met. The effect of the developmental disability and the person's need for services and supports are a result of a "cumulative effect of all the criteria." (Gollay, 1979, p.3)

The age of onset delineates two points: first, the disability occurs during the developmental period, making it difficult for the person to acquire necessary skills, and, second, the difficulty must be demonstrated during the developmental period.

Thus, as Gollay (1979) writes, "a developmental disability is a disability which has such a pervasive, cumulative and early impact on an individual that the person is likely to require long term care throughout life." (P.4)

The major difference between the definition of mental retardation (MR) and developmental disability (DD) are the later age of onset (age 18 for MR vs. age 22 for DD) and absence of reference to IQ for developmental disabilities.

Usually people with mental retardation, cerebral palsy, autism spectrum disorder, various genetic and chromosomal disorders such as Down syndrome are described as having developmental disabilities. HOWEVER, when determining eligibility, the relevance and applicability of the DD definition must be made consistent with current HCP/CDDO policy.

***(The Modified Definition of Developmental Disabilities. An Initial Exploration*, 1979, Elinor Gollay, Ph. D., U.S. Dept. of Health Education and Welfare.)**

DEVELOPMENTAL DISABILITY ELIGIBILITY PROTOCOL

CRITERIA

A. Does the person have a **severe, chronic developmental disability**? (Specialist physicians, therapist, or psychologists are the most likely professionals to have the capacity and techniques to assess this criterion)

1. Yes - Is it attributable to a mental and/or physical impairment?

a) Yes - Is the mental impairment due to something other than **mental illness** alone, or is the **mental or** physical impairment due to something other than infirmities of aging?

Yes - Proceed to step B of this protocol.

(i) No - The person is not eligible: send a **written notice**, including the right to a local independent **reconsideration consistent with HCP/CDDO Policy on Eligibility Determination** and refer the person to the Community Mental Health Center or the Agency on Aging, Independent Living Center, or other appropriate agency.

FURTHER EXPLANATION

(The Modified Definition of Developmental Disabilities. An Initial Exploration, 1979, Elinor Gollay, Ph. D., U.S. Dept. of Health Education and Welfare.)

The definition **[of developmental disability (DD)]** emphasizes in its introductory phrase the chronic and severe nature of a developmental disability. This phrase does not modify or add to the content of the following elements but simply reinforces their meaning.

By using more general terminology, the definition is left open, potentially, to individuals with any type of condition if they meet the subsequent criteria of the definition. This approach has been selected rather than attempting to list all the possible conditions which could share common attributes, and rather than continuing to list selected conditions. The listing of selected conditions tends to limit developmental disabilities only to those listed despite the broader intent.

Other mental and/or physical conditions which could be considered in determining developmental disability are Cerebral Palsy (CP), Traumatic Brain Injury (TBI), Autism, Muscular Dystrophy (MD), and Asperger's Disorder. This does not include individuals who are solely and severely emotionally disturbed or seriously or persistently mentally ill or have disabilities solely as the result of the infirmities of

(b) No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration consistent with HCP/CDDO Policy on Eligibility Determination**.

2. No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration consistent with HCP/CDDO Policy on Eligibility Determination.**

B. Were **substantial** functional limitations **(based on skill level, not a willingness or unwillingness to perform a task)** clearly demonstrated before age 22? (Parent, physician, teacher, and social worker are the most likely to have the capacity to access this criterion.)

1. Yes - Proceed to step C of this protocol.

2. No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration consistent with HCP/CDDO Policy on Eligibility Determination.**

C. Is the **mental/physical impairment** likely to continue **indefinitely**? (Specialist physicians or therapists are the most likely to be able to assess the criterion.)

1. Yes - Proceed to step D of this protocol.

aging. Vision/hearing impairment, Attention Deficit/Hyperactivity Disorder (ADHD), learning disorders, etc. as a sole diagnosis does not qualify as a severe, chronic disability. Refer to current HCP/CDDO Eligibility policy for additional detail.

There are a host of impairments and conditions which originate during childhood, including various hereditary diseases and congenital defects which do not manifest themselves until adulthood. Indeed, the evidence is continually mounting that many adult conditions may well have their origin in childhood.

A developmental disability is not only one which begins during the developmental period, but one which also has its impact during development such that it interferes with normal acquisition of skills and normal activities.

The intent of this criterion is to indicate that developmentally disabled persons will, in all likelihood, remain severely handicapped and in need of support throughout their lives. However, the concept is purposefully left ambiguous because of the fact that for some developmentally disabled individuals' appropriate intervention will reduce the substantiality of their **functional limitations**. The criterion is purposefully worded not to be overly optimistic (to suggest that with appropriate intervention many developmental disabilities can be considerably

2. No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration** **consistent with HCP/CDDO Policy on Eligibility Determination.**

reduced in their impact on a person), and not to be overly pessimistic (by implying that all developmental disabilities are expected to last throughout a person's life as a major limiting force). **In some situations, a periodic re-determination of eligibility may be needed. This is appropriate and consistent with HCP/CDDO Policy on Eligibility Determination.**

D. Does the person, if six years old or older, currently demonstrate **substantial** functional **(based on skill level, not a willingness or unwillingness to perform a task)** limitations in three or more of the following areas of major life activity (defined in Glossary):
___ **self-care**; (HCP policy definition added to glossary)
___ **receptive and expressive language**;
___ **learning**;
___ **mobility**;
___ **self-direction**;
___ **capacity of independent living**; and
___ **economic self-sufficiency**.
(If this criterion is not immediately obvious, use one of the assessment instruments **for determining substantial functional limitations as** listed in the Glossary.)

The purpose of this stipulation is to indicate that the functional limitation experienced by an individual is pervasive. To include individuals with **substantial** limitations in less than three areas would have considerably reduced the overall substantiality and pervasiveness of the individuals included beyond those who are the most severely handicapped. It is the impact of having a combination of limitations that differentiates people who are developmentally disabled from other people who have a severe handicap.

This criterion reinforces both the **substantial** and the extended nature of a developmental disability. It also further reinforces the pervasiveness and complexity of developmental disabilities. This criterion serves as an important additional dimension to consider when attempting to determine whether or not someone meets the criteria of substantiality and chronicity. In particular, a person only meets the criterion of substantiality if the **functional limitations** result in the need for a variety of services, and only meets the criterion of chronicity if the need for services and supports continues for an extended period. Of crucial importance is the need for planning to cover a potential lifetime of service needs.

(NOTE: If the person is under six years old, skip to step I.)

1. Yes - Proceed to step E of this protocol.

2. No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration** **consistent with HCP/CDDO Policy on Eligibility Determination.**

E. Does the person need a **combination** of more than one type of service, care, or treatment?

1. Yes - Proceed to step F of this protocol.

2. No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration** **consistent with HCP/CDDO Policy on Eligibility Determination.**

F. Does the **person need a** **combination** of service**s**, care or treatment **which** need**s** to be **sequenced** over a **prolonged** (potentially lifelong) period of time? **THE RESPONSE SHOULD BE BASED ON THE NEED OF THE SERVICES NOT THE AVAILABILITY.**

1. Yes - Proceed to step G of this protocol.

2. No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration** **consistent with HCP/CDDO Policy on Eligibility Determination.**

Examples of service, care or treatment include: seeing a doctor regularly due to a medical condition; physical therapy; occupational therapy; speech services; assistive/mobility devices; dietary services; assistance with medications; coordination of support services and/or activities of daily living; transportation; and, attendant care.

G. Does the person need services, care, or treatment provided by people trained in a variety of **disciplines**?

1. Yes - Proceed to step H of this protocol.

2. No - The person is not eligibly; send a **written notice**, including the right to a local independent **reconsideration consistent with HCP/CDDO Policy on Eligibility Determination.** .

H. Do the services, care, or treatment need to be **individually planned and coordinated** concurrently and over time? **(This question is about need – it is not about who does the planning or coordination, or the person's ability to do the planning or coordination.)**

1. Yes - The person is eligible.

2. No - The person is not eligible; send a **written notice**, including the right to a local independent **reconsideration consistent with HCP/CDDO Policy on Eligibility Determination.**

I. Does the child **(under age six)** demonstrate at least three **developmental delays** **of 25 percent or more** as measured by qualified professionals using appropriate diagnostic instruments or procedures? **Still looking for source of reference on "of 25 percent or more"**

1. Yes - Go back to step E.

2. No - The child is not eligible; send a **written notice**, including the right a local independent **reconsideration** **consistent with HCP/CDDO Policy on Eligibility Determination.**

GLOSSARY

Axis II Diagnosis (of mental retardation): one of the following diagnostic categories as defined in the ***Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision. Washington, DC, American Psychiatric Association, 2000.**

317 - Mild Mental Retardation
318.0 - Moderate Mental Retardation
318.1 - Severe Mental Retardation
318.2 - Profound Mental Retardation
319.0 – Mental Retardation NOS

Capacity for independent living is the ability to be self-governing and self-sustaining. For people with developmental disabilities, independent living is often accomplished within a supportive service network that provides protection with maximizing independence for that person. Although this may mean something as simple as home health and adaptive equipment for negotiating the environment, services may also included many life skills supports for people with greater cognitive impairments. These include supports such as transportation, community and home-based supports, budget monitoring and sheltered or supported work.

Developmental Delay (Assessment Tools)

Note: Instruments commonly used to identify developmental delays include the:

1. Denver Developmental Screening Test (DDST);
2. Early Intervention Developmental Profile (EIDP);
3. Developmental Screening Inventory (DSI);
4. Gesell Developmental Schedules
5. **Leiter International Performance Scale-Revised (Leiter-R)**
6. **Childhood Autism Rating Scale (CARS)**

Disciplines: More than one type of profession or recognized, specialized training.

Economic self-sufficiency means that a person has a job or other source of income that results in financial independence.

Functional Limitations: inability to independently perform a variety of necessary tasks related to everyday life. **This is about skill level, not the willingness or unwillingness to perform a task.**

Indefinitely: without a foreseeable end or change.

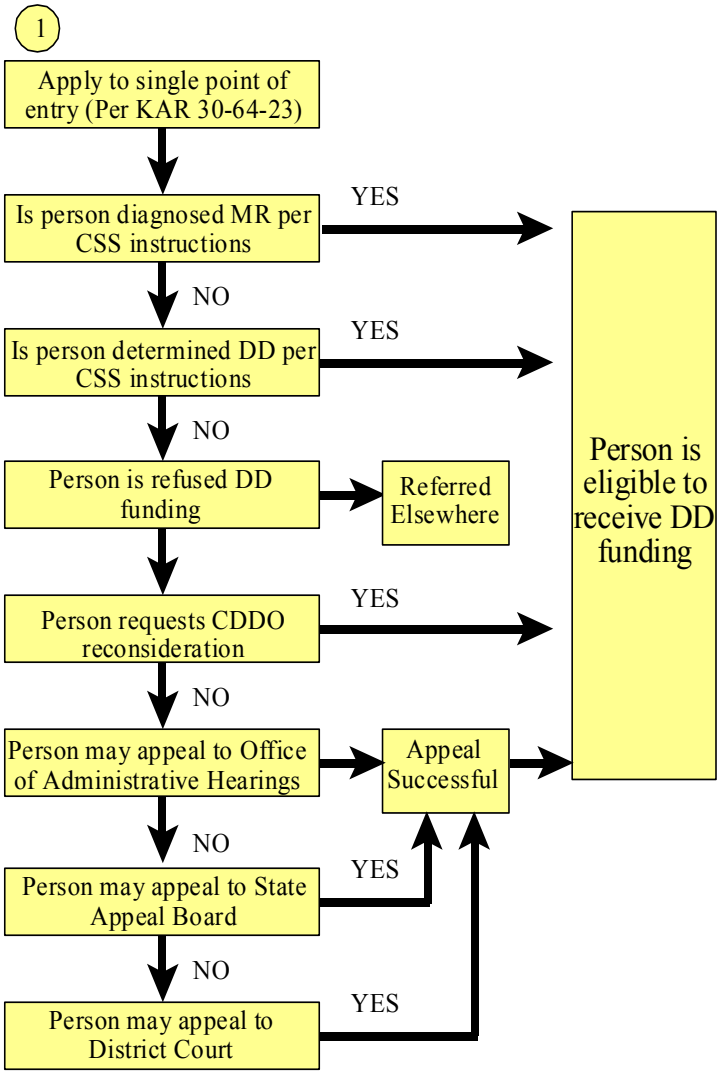
Sequenced: More than one activity following one another over time.

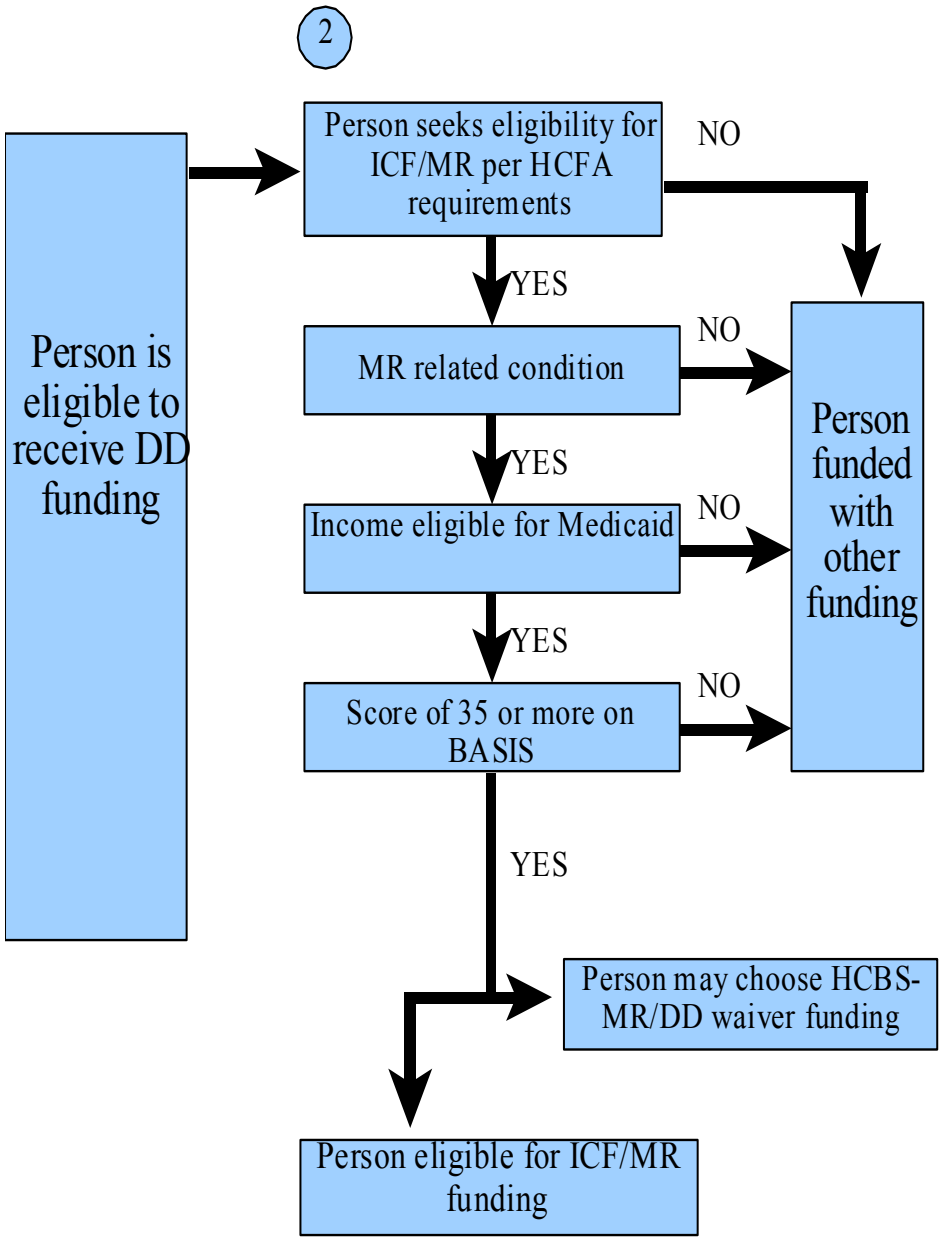
(continued)

Clinical judgment is a special type of judgment rooted in a high level of clinical expertise and experience; it emerges directly from extensive data. It is based on the clinician's explicit training, direct experience with people who have mental retardation, and familiarity with the person and the person's environments. Thus clinicians who have not gathered extensive relevant assessment data should not claim clinical judgment. Combination: More than one concurrent activity. Developmental Delays: demonstrated difficulty performing one of more set of skills (e.g. gross or fine motor, reception or expressive language, etc.) at the level expected for a child's age. Individually Planned and Coordinated: arranged for each person with explicit needs, goals, objectives, time frames, or procedures identified for that person and managed **if needed** by a separate person or process which assures the services and supports are not conflicting or duplicative at any given time or over time. **Learning is the ability to acquire new behaviors, perceptions and information. Learning is also the ability to apply knowledge gained in the past to new situations.** Mental Illness: a mental or bodily condition marked primarily by sufficient disorganization of personality, mind, and emotions to seriously impair the normal psychological functioning of the individual.	Severe, Chronic Disability: having great consequence, of long duration, pervasive; the person must meet ALL the criteria listed in the protocol. This would imply extreme variation from the general population in capabilities as well as a condition of long duration that is likely to continue indefinitely. **Self-care: Skills involved in toileting, eating, dressing, hygiene and grooming. (definition from HCP policy)** **Self-direction involves the ability to decide what to do. Individuals who are self-directed manage relationships; decide when, where and what to eat; recognize the need and arrange for appropriate medical care; can express personal opinions. A person who has the ability to make decisions affective and protection personal self-interest is self-directed. (SRS proposing another definition)** ***(continued)***

Mental/Physical Impairment: a condition of the mind and/or body that results in decreased mental and/or physical capacity. **Mobility involves the ability to move from one place to another. A person who is mobile may use a wheelchair (or other aids, such as crutches or a cane) or walk unassisted.** Prolonged: Extending over a long period of time. **Receptive and expressive language: A person who understands others has receptive language. A person who expresses ideas and gives information to others is using expressive language. Receptive and expressive language can be verbal (speech) or involve nonverbal communication such as symbols, gestures or touch cues.**	Substantial: a considerable degree or extent; as relate to functional limitation, the inability to independently perform necessary tasks is considerable; i.e., the person requires a great deal of assistance to perform them or that someone perform them for the person. Note: If it is not clearly evident the person has substantial functional limitations a number of assessments are available to help determine this. Some of those assessments include the: 1. AAMD Adaptive Behavior Scales (ABS); 2. Vineland Adaptive Behavior Scales; 3. Scales of Independent Behavior **– revised (SIBR);** 4. Inventory for Client and Agency Planning (ICAP); 5. Comprehensive Test of Adaptive Behavior; 6. Eligibility Determination Instrument (EDI); **and,** **8. Street Survival Skills Questionairre (SSSQ).** ***Some definitions taken from Handbook – Dual Diagnosis: Assessment, EPICS, Kansas University Affiliated Program, Parsons, Kansas***

DD ELIGIBILITY




2
Person is eligible to receive DD funding
Person seeks eligibility for ICF/MR per HCFA requirements
NO
YES
MR related condition
NO
YES
Income eligible for Medicaid
NO
YES
Score of 35 or more on BASIS
NO
YES
Person funded with other funding
Person may choose HCBS-MR/DD waiver funding
Person eligible for ICF/MR funding

SERVICE DISPUTES